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## Medical ethics and literature

# Autonomy in the face of a devastating diagnosis

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### Abstract

*Literary accounts of traumatic events can be more informative and insightful than personal testimonials. In particular, reference to works of literature can give us a more vivid sense of what it is like to receive a devastating diagnosis. In turn this can lead us to question some common assumptions about the nature of autonomy, particularly for patients in these circumstances. The literature of concentration camp and labour camp experiences can help us understand what it is like to have one's life-plans altered utterly and unexpectedly. Contrary to common views of autonomy which have difficulty in characterising autonomous action when long-standing assumptions are suddenly lost, these examples show that autonomy is possible in these circumstances. We need a theory of autonomy which can deal with traumatic events and is useful in the clinical context.*

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Literature can give us insights into the way a person experiences a devastating diagnosis. Literary accounts of traumatic events sometimes capture the experience better than personal testimonials. Paradoxically, they seem more vivid and life-like. For obvious reasons, reports written specifically in order to show how people experience life-threatening illnesses are usually written retrospectively, after the initial crisis has eased. The focus then tends to be on re-building one's life. This seems to be the case in *Quest For Life* and *Spirited Women*<sup>1</sup> which are based on the experiences of hundreds of people who have experienced life-threatening illnesses. In *Quest For Life* one woman explains that the sense of remoteness in her story is caused by her need to move on from the pain she felt at the time of diagnosis: "Instead, I'm writing somewhat from a distance".<sup>2</sup>

When people receive devastating diagnoses, they find themselves, more or less suddenly, in a dramatically different world. They may act in ways that could be interpreted as a departure from a

previously held life-plan or stable values. This raises an issue for standard theories of autonomy that emphasise the idea of people as enduring entities, with values that persist, and with plans for the future. In the clinical context people often find themselves with their life-plans shattered and with altered selves. The onset of a life-threatening illness is a random traumatic event involving disintegration of one's life-plan. There is a difficulty, therefore, in determining whether a person in this situation is acting autonomously, particularly if he or she makes a decision to refuse treatment or go against what is recommended. People who, under emotional or other stress, depart from their previously held values or plans, may be seen as not acting autonomously.

Aleksandr Solzhenitsyn's writings give us an insight into how a victim of cancer experiences the devastation of a sudden illness:

"The hard lump of his tumour - unexpected, meaningless and quite without use - had dragged him in like a fish on a hook and flung him on to this iron bed - a narrow, mean bed, with creaking springs and an apology for a mattress. Having once undressed said goodbye to the family and come up to the ward, you felt that the door to all your past life had been slammed behind you."<sup>3</sup>

Rusanov experiences a shattered life-plan: "His whole happy life, so well thought out, so harmonious and useful, was now about to crack." His sense of self is also altered: "In a matter of hours he had as good as lost all his personal status, reputation and plans for the future - and had turned into eleven stones of hot, white flesh that did not know what tomorrow would bring."<sup>4</sup> Despite his predicament, there is no suggestion that Rusanov is not competent or capable of making his own decisions. On the contrary, he seems remarkably in touch with reality and seems to have a clear insight into his situation.

Let us consider autonomy in the light of Solzhenitsyn's portrayal of cancer sufferers, then

following that, in the light of literature portraying survivors of concentration and labour camps. Existing, well developed theories tend to construe autonomy as a feature of persons or an ideal of character. Various accounts exist and although there are differences between them, they also have some things in common. Autonomy is usually conceived as a psychological state; a kind of psychological maturity which we judge on the basis of what we see people doing or saying. It is a goal to be pursued and promoted.

In these accounts there is often an emphasis on long term planning. According to Robert Young: "the self-directedness of one's life is exemplified by the fact that, in the main, it is ordered according to a plan or conception which fully expresses one's own will".<sup>5</sup> This relates to things like career, life style and what he calls "dominant pursuits". He claims it is the "following through" on that plan or conception that unifies the various pursuits and it is that on which we base our judgments about autonomy.<sup>6</sup>

Other components of psychological autonomy are rationality, independence and self-control. According to one view, an autonomous person is independent, rational and possesses personal integrity, where personal integrity consists of internal coherence of psychological elements such as thoughts and desires. A unified persona is a requirement. On this view, and in common with other psychological accounts, rationality is to do with achieving our ends. As autonomous agents we are "essentially purposive", and we seek ways to effect our short and long term goals. The rationality defended here is instrumental rationality.<sup>7</sup>

### **Authenticity**

Preferences and desires are central to psychological accounts of autonomy. Autonomy is sometimes tied in with the idea that some kind of critical reflection on one's first-order desires and preferences by higher-order desires and preferences is an indication of autonomy. It suggests that we are not only doing what we want, but what we "want to want".<sup>8</sup> This introduces the idea of authenticity as a possible condition of autonomy.

Diana T Meyers claims that an autonomous person lives in harmony with his or her authentic self and a person's true or authentic self cannot be expressed if he or she has no life-plan. To be without a life-plan is to be without "pre-affirmed dispositions" and "pre-established policies". This involves the burdensome and time-consuming chore of consulting one's self at length about each personal decision.<sup>9</sup> Meyers also adopts John Rawls's "principle of responsibility to self" which stems from the idea that people are "enduring

entities" who should provide for their futures. According to Rawls's principle: "the claims of the self at differing times are to be so adjusted that the self at each time can affirm the plan that has been and is being followed".<sup>10</sup>

### **Coherence and continuity**

Common to these accounts is coherence and continuity of some sort, which is expressed in a person's character and through his or her life-plan. There is also an underlying assumption that there is stability and coherence in the world. However, when bad things happen in an arbitrary and haphazard way, the stability and coherence assumed in these theories can be destroyed. The significance of this for these theories of autonomy is that they cannot really differentiate autonomous actions from actions that are not autonomous. They can only understand autonomy in terms of coherence with an enduring set of values or life-plan. In the circumstance already mentioned, when a patient refuses what the doctor regards as a reasonable recommendation, the question of whether the patient is acting autonomously in refusing it will not be satisfactorily answered. The theories referred to do not take adequate account of the idea that a person's whole outlook and perception of the future may change when things happen in a haphazard and arbitrary way.

While illustrating the idea that autonomy is possible in the face of a devastating diagnosis, some literary works suggest that standard theories of autonomy may be somewhat idealistic or fanciful. Prisoners may experience their imprisonment as a random or traumatic event, somewhat like the diagnosis of an illness. They may suffer disruption to life-plans and to their sense of self. Literary accounts of concentration or labour camp experiences, where prisoners dominate or influence their fate rather than succumb to it, show us how autonomy is possible.

It may be objected that the comparison between a patient and a prisoner is faulty. Pellegrino and Thomasma argue that a prisoner is deprived of freedom and civic rights and asks only to be released from prison, but illness is a unique predicament. Illness is a state of "wounded humanity" in which the body intrudes on our existence - we must serve it rather than it serving us.<sup>11</sup> They claim that illness "deprives the patient of his distinctly human freedoms - to act, to make his own decisions, to be independent of the power of others. The integrity of the patient's self-image as a human is shattered, or at the very least, threatened".<sup>12</sup> Pellegrino and Thomasma make the extraordinary claim that "the patient is no

longer free to make rational choices among alternatives".<sup>13</sup>

Pellegrino and Thomasma's view of illness captures the disruption that a devastating diagnosis has on a person's sense of self and his or her life-plans, however, while illness may make us vulnerable it does not entail such a passive role for patients as they propose. In *Cancer Ward* we see how patients can become dehumanized because of a loss of specific freedoms, such as making decisions for themselves. However, this is not necessarily brought about by the state of illness. Possibly it is as much to do with the way patients are treated:

"No sooner does a patient come to you than you begin to do all his thinking for him. After that, the thinking's done by your standing orders, your five minute conferences, your programme, your plan and the honour of your medical department ... I become a grain of sand ... nothing *depends* on me."<sup>14</sup>

This suggests that patients who are able to make choices and take an active part in decisions, have some control over their fate. There is some similarity in Viktor Frankl's claim that it was the opportunity to make decisions that could prevent a prisoner from becoming "the plaything of circumstances". Viktor Frankl was a concentration camp survivor whose book, *Man's Search For Meaning*, is a classic example of survival under adverse conditions.<sup>15</sup>

Some people are still able to determine what becomes of themselves even when they have had to jettison their life-plan. In describing his admission to Auschwitz, Frankl tells how, in the anteroom of the disinfecting chamber, he and the other new arrivals were told to leave all of their possessions. Like some of the others, Frankl cannot grasp the fact that everything is to be taken away. He has with him a manuscript he has been writing and he does not want to give that up. He tells how he tried to confide in one of the old prisoners:

"Approaching him furtively, I pointed to the roll of paper in the inner pocket of my coat and said, 'Look, this is the manuscript of a scientific book, I know what you will say; that I should be grateful to escape with my life, that that should be all I can expect of fate. But I cannot help myself. I must keep this manuscript at all costs; it contains my life's work. Do you understand that?' Yes, he was beginning to understand. A grin spread slowly over his face, first piteous, then more amused, mocking, insulting, until he bellowed one word at me in answer to my question, a word that was ever present in the vocabulary of the camp inmates:

'Shit!' At that moment, I saw the plain truth and did what marked the culminating point of the first phase of my psychological reaction: I struck out my whole former life."<sup>16</sup>

By mentally extricating himself from his plans and something that he values greatly, Frankl secures his psychological survival but also obliterates his life-plan. This suggests that he was able, to some extent, to determine what would become of himself without a life-plan. It does not follow, however, that Frankl and his fellow prisoners were no longer autonomous:

"The illusions some of us held were destroyed one by one, and then, quite unexpectedly, most of us were overcome by a grim sense of humor. We knew that we had nothing to lose except our ridiculously naked lives."<sup>17</sup>

Frankl tells us how it is, when all the familiar goals are taken. Prisoners who dwell on the fact that they did not know how long their term was, suffered the most. The whole structure of their life changed for the worse. Everything became pointless. He claims, however, that there is one human freedom that cannot be taken away; it is "to choose one's attitude in any given set of circumstances, to choose one's own way".<sup>18</sup> Even in a concentration camp, there were opportunities to make choices. If a prisoner missed those opportunities because of an inability to see any future goal, he was "robbing the present of its reality".<sup>19</sup>

Another instance of autonomy without a life-plan comes from Aleksandr Solzhenitsyn's *One Day In The Life Of Ivan Denisovich*.<sup>20</sup> It is a dramatic, but, plotless account of a single day in the life of a prisoner in a soviet labour camp. Ivan Denisovich's struggle for survival involves making choices which are fateful and never-ending. Rather than a life-plan this is a "validation of the moment."<sup>21</sup> Through Ivan Denisovich, Solzhenitsyn gives us a picture of someone for whom nothing goes beyond a day or even a moment in terms of a plan.

There is great significance in momentary gains for Ivan Denisovich. Solzhenitsyn slows time with his detailed descriptions, in particular the descriptions of Ivan Denisovich's pleasure in eating:

"He began eating. First he just drank the juice, spoon after spoon. The warmth spread through his body, his insides greeted that skilly with a joyful fluttering. This was it! This was good! This was the brief moment for which a zek lives."<sup>22</sup>

Even the meagre transitory gain such as a ladleful of watery soup has significance: "For the moment that ladleful means more to him than freedom,

more than his whole past life, more than whatever life is left to him.”<sup>23</sup> Through Ivan Denisovich's victories and defeats we see the value of a moment for its own sake rather than its place in some overall plan.

Solzhenitsyn makes us aware of the arbitrary rulings that can affect Ivan Denisovich and the futility of forming goals. Ivan Denisovich mourns the fact that he has lost one of the habits that was necessary when he was free. He had lost the habit of planning how he was going to support his family “from day to day or year to year”. But, in his situation: “that somehow made life easier”. He is able to think about what he might do when he is released but to make plans is a doubtful exercise: “Only - would they ever let him go? Maybe they'd slap another ten on him, just for fun?”<sup>24</sup>

Within the camp, within the reality of the confines of his situation, Ivan Denisovich has some control over his life. By immersing himself in the minutiae of living he has an active role in how his life goes. His concern with the minor details of day-to-day living clears the way for an easier adjustment to circumstances. This is evident in his elation when he manages to get hold of, not only a pair of shoes, but felt boots as well: “Life was a bed of roses, no need to die just yet”.<sup>25</sup> There is an implication here that he will need to die, quite possibly fairly soon. It reinforces the idea that a life-plan is of little use to Ivan Denisovich. However, it does not suggest that he cannot determine, to some extent, the course of his life.

Literary accounts of survival show that, rather than being overwhelmed by a traumatic event, people can be autonomous in the sense that they can control or influence their fate to serve their purposes. The picture we have of Ivan Denisovich, at the finish of his day is not the picture of a person who is a “plaything of circumstances”. In fact he expresses some satisfaction with life: “The end of an unclouded day. Almost a happy one”.<sup>26</sup> These examples suggest that we may want to view

autonomy differently. We may want to view it as task-related rather than plan-related. We may also want to be more open to the possibility that a devastating diagnosis can lead to behaviour that is autonomous, but not part of an overall larger plan. This subsequently casts doubt on the usefulness of standard theories of autonomy.

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## References

- 1 King P. *Quest for life*. Sydney: Random House, 1992; King P. *Spirited women: journeys with breast cancer*. Sydney: Random House, 1995.
- 2 See reference 1: *Quest for life*; 353-4.
- 3 Solzhenitsyn A. *Cancer ward* translated by Bethell N and Burg D. London: Penguin books, 1971:17-18.
- 4 See reference 3: 33,19.
- 5 Young R. *Personal autonomy: beyond negative and positive liberty*. London: Croom Helm, 1986:8.
- 6 See reference 5:109.
- 7 Berofsky B. *Liberation from self: a theory of personal autonomy*. New York: Cambridge University Press, 1995: 9-11.
- 8 Frankfurt HG. Freedom of the will and the concept of a person. *Journal of Philosophy*. 1971; 68: 5-20. Lindley R. *Autonomy*. London: Macmillan, 1986: 64-7. Dworkin G. *The theory and practice of autonomy*. Cambridge: Cambridge University Press, 1988: 15-20.
- 9 Meyers DT. *Self, society, and personal choice*. New York: Columbia university Press, 1989: 51.
- 10 See reference 9: 117.
- 11 Pellegrino ED, Thomasma DC. *A philosophical basis of practice: toward a philosophy and ethic of the healing professions*. New York: Oxford University Press, 1981:207-9.
- 12 See reference 11: 252.
- 13 See reference 11: 208-9.
- 14 See reference 3: 85-6.
- 15 Frankl VE. *Man's search for meaning* translated by Lasch I. London: Hodder and Stoughton 1964: 65-6.
- 16 See reference 15: 12.
- 17 See reference 15: 14.
- 18 See reference 15: 65.
- 19 See reference 15: 71.
- 20 Solzhenitsyn A. *One day in the life of Ivan Denisovich* translated by Willetts HT. London: The Harvill Press, 1996.
- 21 Aucouturier M. Solzhenitsyn's art. In: Feuer K, ed. *Solzhenitsyn: a collection of critical essays*. New Jersey: Prentice-Hall, 1976: 29.
- 22 See reference 20: 126.
- 23 See reference 20: 112.
- 24 See reference 20: 34-5.
- 25 See reference 20: 9.
- 26 See reference 20: 150.

## News and notes

### Qualitative Research in Health and Social Care

A conference on qualitative research in health and social care will be held from April 30-May 1, 1998, in Bournemouth, England. Speakers will include: Professor Paul Atkinson, Dr Philip Burnard, Professor Malcolm Hill and Professor Yvonna Lincoln.

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